AMENDED IN ASSEMBLY JUNE 15, 2010 AMENDED IN SENATE APRIL 29, 2010

Senate Joint Resolution

No. 23

Introduced by Senator Simitian (Coauthors: Senators Alquist, Cox, Leno, Negrete McLeod, and Strickland)

February 19, 2010

Senate Joint Resolution No. 23—Relative to research for mitochondrial disease.

LEGISLATIVE COUNSEL'S DIGEST

SJR 23, as amended, Simitian. Mitochondrial disease: federal support for research.

This measure would urge the President and Congress of the United States to take the action necessary to amend the federal statutes to support research for mitochondrial disease.

Fiscal committee: no.

- WHEREAS, Mitochondrial diseases result when there is a defect that reduces the ability of the mitochondria in a cell to produce energy. As mitochondria fail to produce enough energy, the cells will cease to function properly and will eventually die. Organ systems will begin to fail, and the life of the individual is
- 6 compromised or ended; and
- WHEREAS, Mitochondria are organelles within most human cells that convert oxygen and calories into the energy the cell needs
- 9 to power activity and sustain human life. If mitochondria
- 10 malfunction, there is a lack of cellular energy to perform functions

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1 and an accumulation of byproducts that may impair or destroy the 2 cell; and

WHEREAS, Mitochondrial diseases are a relatively newly diagnosed group of diseases, first recognized in an adult in the 1960s and in the 1980s for pediatric onset cases. Mitochondrial diseases are underdiagnosed and the diagnosis of these diseases is extremely difficult; and

WHEREAS, Mitochondrial diseases can present themselves at any age, with associated mortality rates that vary depending upon the particular disease. Mitochondrial diseases generally cause progressive deterioration and weakness. The most severe diseases result in progressive loss of neurological and liver function, and death within several years; and

WHEREAS, According to the National Institute of Environmental Health Sciences, half of the individuals affected by a mitochondrial disease are children. When these children show symptoms before age five, approximately 80 percent will not survive beyond age 20. Researchers estimate that one in 4,000 children will develop a mitochondrial disease related to an inherited mutation by age 10, and that 1,000 to 2,000 children born annually in the United States will develop a mitochondrial disease in their lifetime; and

WHEREAS, There are over 40 mitochondrial diseases, and mitochondrial dysfunction is associated with many disorders including neurological diseases like Parkinson's, Alzheimer's, ALS, and autism, as well as other diseases associated with aging, diabetes, and cancer; and

WHEREAS, Mitochondrial diseases are most commonly the result of an inherited or spontaneous genetic mutation, either in the nuclear or mitochondrial DNA. Some mitochondrial diseases have been attributable to environmental factors that interfere with mitochondrial function; and

WHEREAS, There is no cure for mitochondrial disease; and

WHEREAS, Improving understanding of mitochondrial function and disease has wide potential application to areas of biomedical research. Understanding mitochondrial disease could uncover treatments for a range of serious diseases; and

WHEREAS, The United Mitochondrial Disease Foundation has designated the week of February 15 to February 19, 2010, as "CALL TO ACTION" week to encourage support for federal

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efforts to enact mitochondrial disease research and treatment 2 legislation; and 3

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WHEREAS, Pursuant to Assembly Concurrent Resolution No. 25 (Res. Ch. 15, 2009) the third full week in September in each year the Legislature has proclaimed Mitochondrial Disease Awareness Week, and has urged Californians to observe the week with appropriate activities and programs; now, therefore, be it

Resolved by the Senate and the Assembly of the State of California, jointly, That the Legislature of the State of California urges the President and Congress of the United States to take the action necessary to amend the federal statutes to support research for mitochondrial disease; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the President and Vice President of the United States, to the Speaker of the House of Representatives, to the Senators and Representatives from California in the Congress of the United States, and to the author of this resolution for appropriate distribution.